

# HIV/AIDS Stigma: An Impediment to Public Health

Stigma is not new to public health, nor is it unique to HIV/AIDS. History provides an unfortunate abundance of examples of “prejudice, discounting, discrediting, and discrimination”<sup>1</sup> directed toward persons who are ill or perceived to be ill. Leprosy was viewed as divine punishment for moral misconduct in centuries past, and persons infected with *Mycobacterium leprae* were forcibly excluded from both civil and religious society.<sup>2</sup> Those who became ill with cholera in the early years of our American republic were publicly decried as intemperate, lazy, and vice ridden.<sup>3</sup> Even after the germ theory became widely accepted, discrediting divine wrath, miasma, and other incorrect theories of disease, negative attitudes lingered. For example, some persons with syphilis were “innocent”; others were not. Often, physicians were reluctant to treat patients in the latter category, considering them immoral and hence unworthy of care.<sup>4</sup>

## GOOD NEWS, BAD NEWS ABOUT HIV/AIDS STIGMA

Given stigma’s enduring profile across time, cultures, and circumstances, the results obtained by Herek and his colleagues, reported in this issue of the Journal, are not altogether unexpected. The good news is that Herek et al. found that overt expressions of HIV/AIDS stigmatization had decreased during the 1990s. The bad news is that in 1999, nearly 1 in 5 American adults they surveyed said they “feared” persons with AIDS. One in 6 admitted to feelings of “disgust” related to persons with AIDS.<sup>5</sup> Another study conducted in 2000, a national Internet survey of more than 5600 Ameri-

can adults, revealed similar findings. Nearly 1 in 5 respondents agreed with the statement “People who got AIDS through sex or drug use have gotten what they deserve.”<sup>6</sup>

The knowledge that a disease caused by HIV infection, whose acquisition is prominently associated with sexual and drug-using behaviors, is capable of provoking intense, value-laden reactions such as those described above is, perhaps, not surprising. But to view the findings of Herek and his colleagues merely as additional documentation of the fear, negativity, and judgmental attitudes that can be elicited by HIV/AIDS is to miss the point. To underestimate the insidious power of stigma is to risk the very success of effective HIV prevention and care programs.

## THE EFFECTS OF STIGMA ON THOSE AT RISK

Consider the qualitative research of Stokes and Peterson, who conducted interviews in Atlanta, Ga, and Chicago, Ill, with 76 African American men who have sex with other men.<sup>7</sup> They found compelling evidence that negative attitudes about homosexuality had been internalized by many of their subjects, and they hypothesized several mechanisms through which this “internalized homophobia” may mediate increased HIV risk behavior. Lowered self-esteem may negate motivators for self-protection (i.e., the consistent practice of safer sex), lead to multiple sexual encounters in an attempt to seek self-validation, or result in the use of alcohol or drugs—substances that impair judgment and may interfere with a person’s ability to negotiate and practice safer sex—to enable sexual encounters. All

sobering examples of stigma’s ability to substantially interfere with HIV prevention efforts.

The CDC estimates that as many as 300 000 persons living with HIV infection in America are unaware of their infection status.<sup>8</sup> A broad range of studies has shown that, for some of these individuals, fear of receiving a positive test result remains a potent disincentive to seeking HIV testing.<sup>9</sup> To what degree is this fear related to an understandable reluctance to learn that one has a life-threatening illness? How much of it can be ascribed to feelings of shame or concerns about the potential for others to discover one’s HIV infection?

While we cannot distill stigma’s precise contribution to the toll of untested thousands, what we can say with certainty is that clients are more likely to seek out and follow through with HIV testing services that they perceive to be nonthreatening, non-judgmental, and responsive to their individual needs and circumstances. A recent series of focus groups and individual interviews with 73 young men and women (aged 15–19 years) revealed that teenagers are “highly attuned” to health care workers’ attitudes toward them and are less likely to seek HIV testing in environments where they perceive workers to be judgmental about their sexual and drug use behaviors.<sup>10</sup>

People at substantial risk for HIV infection who are not tested in a timely manner because they have previously experienced—or fear that they might come to experience—discounting, discrediting, or judgmental attitudes from health care providers and their staffs are a tangible example of stigma’s impact on our ability to effectively treat HIV/AIDS. After

all, no matter how well federally funded programs such as the Ryan White CARE Act might work to minimize disparities in access to quality care, care for HIV/AIDS cannot begin without the diagnosis of HIV infection. Further, people who are infected with HIV and do not know it are less likely to take steps to prevent spreading the virus to others.

## A COMPLICATED ISSUE

Stigma is a complicated issue that has deep roots in the convoluted domains of gender, race, ethnicity, class, sexuality, and culture. Granted, it is not easily understood, nor is it readily addressed. But public health practitioners must not shy away from the subject of stigma, thinking that it is outside the scope of public health or beyond the reach of their capabilities. Cited among the 10 essential health services of every public health agency are the following activities: empower people about health issues, mobilize communities to solve health problems, develop policies and plans in support of individual and community health, and conduct research to find innovative solutions to health problems.<sup>11</sup> To ensure these essential services in the context of HIV prevention and care, there is no question that we must all—every segment of the public health community—confront the impact of HIV/AIDS stigma.

With so complex a phenomenon, how do we begin to confront the negative impact of HIV/AIDS stigma on public health efforts to prevent, diagnose, and treat HIV/AIDS? Like members of any knowledge-based profession, we start with what we know works. For example, we must continue to educate

successive generations of America's youth about how HIV is and is not transmitted, since we know that stigma is more likely to thrive in an environment of ignorance and half-truths.

We must also continue to put into practice a well-studied and well-documented tenet of health promotion—that programs must reflect the needs and preferences of the groups for whom they are intended. This means being vigilant in ensuring that our programs are not inadvertently stigmatizing to the groups for whom they are intended. Fortunately, in the United States we are mostly beyond the overt instances of blatant stigmatization seen in the earliest days of the HIV/AIDS epidemic. But what about the more subtle or subliminal manifestations?

If a counselor's demeanor signals to an injection drug user that she has no respect for him as a person, will he consider credible the information that she provides? If a physician, assuming that the young man in his office asking questions about AIDS is heterosexual, talks only about the risk of HIV transmission during penile–vaginal intercourse, how effective will this information be? How will an outreach worker respond to an HIV-infected woman who refuses to use condoms because of her strong desire to have children? The effects of HIV/AIDS stigma are not limited to the flagrant, headline-grabbing examples of property destruction, physical violence, and death.

Finally, in confronting the negative impact of HIV/AIDS stigma on public health efforts, we must continue to support research in the domains of intervention, program operations, and policy formulation, research that will add to our understanding of how

stigma hampers society from effectively responding to HIV/AIDS. In its 5-year HIV Prevention Strategic Plan released in January 2001, the Centers for Disease Control and Prevention unequivocally asserts that “stigma hampers prevention” and lists a variety of research and programmatic strategies aimed at minimizing the impact of stigma on HIV prevention efforts.<sup>12</sup>

Certainly, stigma is not the only impediment we face in our attempts to create effective HIV prevention and care programs. Gaps in the scientific knowledge base, inadequate transfer of proven prevention technologies, skills deficits among providers and clients both, and resource constraints are among the many factors influencing the success or failure of our efforts. But undoubtedly, stigma needs to be recognized as a continuing impediment to HIV prevention and care programs. As public health practitioners, it is our responsibility to work toward minimizing the negative health consequences of HIV/AIDS stigma. ■

Ronald O. Valdiserri, MD, MPH

## About the Author

Requests for reprints should be sent to Ronald O. Valdiserri, MD, MPH, National Center for HIV, STD, and TB Prevention, Centers for Disease Control and Prevention, 1600 Clifton Rd, NE (E07), Atlanta, GA 30333 (e-mail: rov1@cdc.gov).

This editorial was accepted November 6, 2001.

## References

- Herek GM, Mitnick L, Burris S, et al. Workshop report: AIDS and stigma. *AIDS Public Policy*. 1998;13:36–47.
- Valdiserri RO. Epidemics in perspective. *J Med Humanities Bioethics*. 1987;8:95–100.
- Duffy J. *The Sanitarians: A History of American Public Health*. Urbana: University of Illinois Press; 1990.
- Brandt AM. *No Magic Bullet: A So-*

*cial History of Venereal Disease in the United States Since 1880*. New York, NY: Oxford University Press; 1985.

- Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999. *Am J Public Health*. 2002;92:371–377.
- Centers for Disease Control and Prevention. HIV-related knowledge and stigma—United States, 2000. *MMWR Morb Mortal Wkly Rep*. 2000; 49: 1062–1064.
- Stokes JP, Peterson JL. Homophobia, self-esteem, and risk for HIV among African American men who have sex with men. *AIDS Educ Prev*. 1998;10:278–292.
- Janssen RS, Holtgrave DR, Valdiserri RO, Shepherd M, Gayle H, DeCock KM. The Serostatus Approach to Fighting the HIV Epidemic: prevention strategies for infected individuals. *Am J Public Health*. 2001; 91:1019–1024.
- Valdiserri RO, Holtgrave DR, West GR. Promoting early HIV diagnosis and entry into care. *AIDS*. 1999;13: 2317–2330.
- Hearing Their Voices: A Qualitative Research Study on HIV Testing and Higher-Risk Teens*. Washington, DC: Kaiser Family Foundation; June 1999.
- Lee P, Paxman D. Reinventing public health. *Annu Rev Public Health*. 1997;18:1–35.
- Centers for Disease Control and Prevention. HIV Prevention Strategic Plan through 2005. January 2001. Available at: [http://www.cdc.gov/nchstp/od/hiv\\_plan](http://www.cdc.gov/nchstp/od/hiv_plan). Accessed December 22, 2001.